Quality improvement in neurology

Epilepsy Update Quality Measurement Set

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Epilepsy is a common, debilitating, and costly disease. It is estimated that 2.2 million people in the United States are diagnosed with epilepsy, and 150,000 new cases of epilepsy are diagnosed in the United States annually.¹ However, epilepsy prevalence might be underestimated due to numerous social issues that accompany a diagnosis of epilepsy.² People with epilepsy have poorer overall health status, impaired intellectual and physical functioning, and a greater risk for accidents and injuries.¹⁻³ It is estimated that the annual direct medical cost of epilepsy in the United States is \$9.6 billion, and this estimate does not include indirect costs from losses in quality of life or productivity.¹

In 2013, the American Academy of Neurology (AAN) formed a multidisciplinary Epilepsy Update Quality Measurement Set workgroup to review the previously released quality measures, as well as to identify and define new quality measures aimed at improving the delivery of care and outcomes for patients with epilepsy.⁴ The first AAN Epilepsy Quality Measures were approved by a similar process in 2009, and as part of the AAN's measure development process undergo a periodic review. During each periodic review, the evidence base is reviewed to determine if existing measures continue to be supported by the evidence, continue to address a treatment gap, or require updates to address new developments in these areas. In this executive summary, we report on the 2014 updated quality measurement set for epilepsy developed by the workgroup (table 1). The full measurement set, including specifications, is available in appendix e-1 on the *Neurology*® Web site at Neurology.org.

The AAN, which has designed and coordinated several quality measurement sets, including for Parkinson disease, dementia, and amyotrophic lateral sclerosis, led this measure development project.⁵⁻⁷ The details of the full AAN measurement development process are available online.⁸ The AAN Epilepsy Update Quality Measurement Set includes measures that can be used in quality improvement initiatives, public reporting, payment, and Maintenance of Certification (MOC) performance in practice programs. Three 2009 epilepsy measures were adopted into pay-for-performance programs.

OPPORTUNITIES FOR IMPROVEMENT Quality epilepsy care includes proper diagnosis, patient and family education, timely referrals, and access to treatment.¹ A review of 261 patient responses using an Internet-based patient survey system indicated that a gap remains between recommended care detailed in the 2009 epilepsy measurement set and the care delivered to patients with epilepsy.⁹

Diagnosis. Providers often fail to gather information on seizure frequency effectively.^{4,9,10} In addition, there is a gap in known seizure etiology.^{4,10-13} According to the International League Against Epilepsy (ILAE), the treatment for differing kinds of epilepsy varies; a treatment for one can be specifically contraindicated in another.¹⁴ This strongly suggests that a clear understanding of each patient's diagnosis by the practitioner would improve patient care.

Education. Research indicates that people with epilepsy frequently misunderstand basic information about epilepsy, including knowledge about their

Supplemental data
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Approved by the AAN Quality and Safety Subcommittee on July 3, 2014; by the AAN Practice Committee on July 18, 2014; and by the AAN Board of Directors on August 6, 2014.

This measurement set was endorsed by the Child Neurology Society on July 29, 2014, and the Epilepsy Foundation on August 7, 2014. This measurement set received a qualified endorsement by the American Epilepsy Society (AES) on July 29, 2013. AES definition of qualified endorsement: Quality measurement sets developed by external organizations that may not meet optimal levels of evidence and/or may not provide complete clinical decision support will be considered for qualified endorsement. The AES may not agree with every recommendation in such a document but overall considers the information to be of educational value to its members and to provide the basis for further analysis and validated measure development.

Go to Neurology.org for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

Table 1 2014 Epilepsy Update Quality Measurement Set

1A. Seizure frequency specified at each encounter (paired measure) (2009 measure revised)
1B. Seizure intervention specified at each encounter (paired measure) (2009 measure revised)
2. Etiology, seizure type, and epilepsy syndrome specified at each encounter (2009 measure revised)
3. Querying and intervention for side effects of antiseizure therapy specified at each encounter (2009 measure revised)
4. Personalized epilepsy safety issue and education provided yearly (2009 measure revised)
5. Screening for psychiatric or behavioral health disorders specified at each encounter (new measure)
6. Counseling for women of childbearing potential with epilepsy yearly (2009 measure affirmed with updated specifications)
7. Referral of treatment-resistant epilepsy to comprehensive epilepsy center every 2 years (new measure)

diagnosis, seizure precipitants or triggers, specific seizure types, the purpose and potential side effects of seizure medications and therapies, safety concerns, and the risks of seizures.^{1,4,15–18} Data from measure testing showed that on average, fewer than 40% of women received counseling about epilepsy and how its treatment may affect contraception and pregnancy.¹⁹ An AAN evidence-based guideline provides recommendations for counseling on these issues.²⁰ People with epilepsy, their families, and their caregivers want more information than they currently receive, and this includes information on sudden unexplained death in epilepsy.^{1,21} Education should be provided in the best manner to meet their specific situations, as patients may not request this information because they are embarrassed or intimidated.

Timely referrals and access to treatment. Evidence indicates that the chance of seizure freedom is substantially reduced after failure of an adequate trial of the first 2 antiseizure medications. This mirrors the ILAE definition, which defines pharmacoresistant epilepsy as failure of adequate trials of 2 tolerated, appropriately chosen and used antiepileptic drugs (whether as monotherapy or in combination) to achieve sustained seizure freedom.^{22,23} Evidence suggests that surgery increases seizure freedom rates often in excess

of 50%, and seizure freedom is related to improved quality of life.^{24,25} The time to referral to epilepsy surgery centers is frequently over 20 years despite evidence of high seizure freedom rates following epilepsy surgery and an AAN evidence-based guideline addressing referral for epilepsy surgery.^{26,27} Many practitioners may not recognize a patient is a surgical candidate for epilepsy. However, referral to a comprehensive multidisciplinary epilepsy center ensures that all potential diagnostic and treatment options are considered and comorbidities are addressed, thus improving the quality of care that patients with epilepsy receive.

METHODS The AAN epilepsy update quality measurement development process followed the same AAN process used to develop the original epilepsy measures.^{4,8} The steps in the measure development process require completing an evidence-based literature search, constructing draft measures and technical specifications, and convening a multidisciplinary workgroup, which was composed of representatives from 17 different professional and patient advocacy organizations to review draft candidate measures. The workgroup met via conference calls and correspondence and convened for a full-day in-person meeting for a robust discussion of the candidate measures. Public comments were solicited during a 30-day period, which included notifications through the organizations represented in the workgroup. The measures and corresponding technical specifications were refined, and approvals obtained from the workgroup, AAN committees, and the AAN Board of Directors.⁸ The workgroup sought to develop measures to support the delivery of high-quality care and to improve patient outcomes. The AAN will continue to update the epilepsy measures on an ongoing basis every 3 years.

RESULTS Epilepsy Update Quality Measurement Set.

The workgroup reviewed the original 8 measures developed in 2008–2009 during a face-to-face meeting on January 23, 2014⁴ (table 2). Appendix e-1 lists the final full measure set with rationale and reasons why a patient may be excluded from specific measures.

The workgroup recommended 3 measures be retired: EEG Results Reviewed, Requested, or Test Ordered (2009 Measure 3); MRI/CT Scan Results Reviewed, Requested, or Scan Ordered (2009 Measure 4); and Surgical Therapy Referral Consideration for Intractable Epilepsy (2009 Measure 6). The 2009 EEG and MRI measures were created to improve accurate diagnosis of seizure type, epilepsy syndrome, and etiology. The need for such tests remains and is reflected in the 2014 Measure 2, but this measure also requires investigating the large number of etiologies that could be investigated in specific situations. Thus, new genetic tests and tests for specific conditions such as autoimmune epilepsies may be needed to meet the 2014 Measure 2 criteria, but no specific tests are required.

Four measures were revised, and the Counseling for Women of Childbearing Potential with Epilepsy

Table 2 2009 Epilepsy measurement set

1. Seizure type(s) and current seizure frequency(ies)
2. Documentation of etiology of epilepsy or epilepsy syndrome
3. EEG results reviewed, requested, or test ordered
4. MRI/CT scan results reviewed, requested, or scan ordered
5. Querying and counseling about antiepileptic drug side effects
6. Surgical therapy referral consideration for intractable epilepsy
7. Counseling about epilepsy-specific safety issues
8. Counseling for women of childbearing potential with epilepsy

measure was affirmed. Two new measures were approved. Screening for Psychiatric or Behavioral Health Disorders (2014 Measure 5) was created as there is now a greater appreciation of the impact of psychiatric comorbidities. The Screening for Psychiatric and Behavioral Health Disorders measure addresses the need for therapy to reduce comorbidity burden and improve quality of life.^{1,28} The 2014 Referral to a Comprehensive Epilepsy Center (2014 Measure 7) was created to encourage access to other nonsurgical interventions available at a comprehensive epilepsy center, as well as confirmation of the diagnosis and to address the prolonged wait for surgical interventions. To fulfill the measure, a referral must be considered every 2 years, but the full measure lists several exclusions, such as already being treated at a comprehensive epilepsy center (appendix e-1).

The workgroup considered several other important constructs in care for people with epilepsy, including ensuring correct diagnosis for treatment-resistant (intractable) epilepsy, quality of life, and self-management. These constructs were not further developed because it was determined that strong evidence was lacking, the gap in care was not large enough, or the opportunity for improvement of the measure was too low. For example, consideration was given to development of a self-management measure; the workgroup did not find consensus on the presence of strong evidence or feasibility of implementing these programs. The concept will be revisited during future measurement updates for potential development as the evidence base may be strengthened. The workgroup developed a measure for a 2-year wait to withdraw anti-seizure medications for children with epilepsy and with a history of focal seizures who exhibited an abnormal EEG, which was included in the draft measurement set distributed for public comment.

The workgroup announced and accepted public comments on the draft measurement set during March and April 2014. During the public comment period, 40 individuals provided 186 comments on the draft measurement set. Decisions to make changes to the proposed measures were based on a majority of comments or if comments raised concerns or issues that were not anticipated in prior discussions. As a result of public comments and concern about the existing evidence, the pediatric antiseizure medication withdrawal measure was withdrawn from the set. The full measurement set including specifications and public comments and workgroup responses is available in appendix e-1.

DISCUSSION The central purpose of the Epilepsy Update Quality Measurement Set is to improve the quality of care provided to patients. However, performance measurement alone does not improve patient

care. Quality measurement has its greatest impact when it is outcome-based and linked directly to quality improvement interventions, public reporting, and payment reforms. These goals were a major focus during the revision. Quality measures are a requisite tool in high-performance health care delivery. Increasingly, measures will be submitted for use in accountability programs, such as payment for reporting or quality of care and MOC. With a focus on patient-centered care, federal, private, and institutional stakeholders expect stretch measures that drive ongoing practice improvement. It is imperative that the neurology and epilepsy communities lead this charge.

The AAN routinely submits developed measures to Centers for Medicare & Medicaid Services for incorporation into accountability programs. The workgroup determined that each of the updated measures is appropriate for consideration in accountability programs. In addition, the AAN will submit the updated epilepsy measures for consideration in the Physician Quality Reporting System (PQRS). From the previous epilepsy measure set, 3 measures were incorporated into PQRS.

While the goal of these measures is to help ensure quality care for epilepsy patients, there is a clear need to clinically validate these measures. The AAN promotes validation of the measures through feasibility, reliability, and validity testing and encourages health science researchers to also pursue this. In particular, it would be helpful if outcomes, either objective or patient-centered, were clinically measured to establish whether adherence to these outcomes made measurable differences. Doing this research could help guide the next set of measures, as well as determine which of the measures make a clinical difference, and should be implemented as an expectation in clinical practice.

The AAN has developed performance in practice programs for MOC, NeuroPI (<http://tools.aan.com/practice/pip/>), which meets the American Board of Psychiatry and Neurology requirements for MOC Performance in Practice requirements. The NeuroPI module for epilepsy will be updated to include changes made in this measurement set. Further validation of the measurement set will be necessary. Assessment of patient outcomes after the successful implementation of these measures will provide data on their utility and determine if this improves care. According to the 2012 Institute of Medicine recommendations for epilepsy care, gaps in care need to be addressed.¹ The 2014 epilepsy measure set can assist providers in addressing these gaps for patients with epilepsy.

AUTHOR CONTRIBUTIONS

Dr. Fountain contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content,

and study supervision. Dr. Van Ness contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/ revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. A. Bennett contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/ revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Absher contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/ revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Patel contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/ revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Sheth contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/ revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Gloss contributed to acquisition of data, analysis or interpretation of data, drafting/ revising the manuscript, and critical revision of the manuscript for important intellectual content. Dr. Morita contributed to acquisition of data, analysis or interpretation of data, drafting/ revising the manuscript, and critical revision of the manuscript for important intellectual content. Dr. Stecker contributed to acquisition of data, analysis or interpretation of data, drafting/ revising the manuscript, and critical revision of the manuscript for important intellectual content.

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Medtronic, and Neuropace; and Dr. Fountain is an epileptologist at an epilepsy program that could potentially benefit from these quality measures by increasing referrals for a higher level of care for treatment-resistant epilepsy. P. Van Ness is an epileptologist at an epilepsy program that could potentially benefit if these quality measures increase referrals for a higher level of care for treatment-resistant epilepsy. A. Bennett and J. Absher report no disclosures. A. Patel serves on the professional advisory board for the Epilepsy Foundation of Ohio, Make-A-Wish, and the Hemispherectomy Foundation; is a consultant for Health Logix, Cyberonics, and GW Pharmaceuticals; has a research grant supported by the Pediatric Epilepsy Research Foundation; has received research support from UCB Pharma and Eisai; and is an epileptologist at an epilepsy program that could potentially benefit if these quality measures increase referrals for a higher level of care for treatment-resistant epilepsy. K. Sheth reports no disclosures. D. Gloss is a paid evidence-based medicine consultant for the American Academy of Neurology and is an epileptologist at an epilepsy program that could potentially benefit if these quality measures increase referrals for a higher level of care for treatment-resistant epilepsy. D. Morita serves on the Board of Directors and Professional Advisory Board of the Epilepsy Foundation of Greater Cincinnati and Columbus, serves as a consultant for Upsher-Smith Laboratories, receives research support from UCB, received research support from Eisai, received honoraria as a consultant for PeerView Press, and is an epileptologist at an epilepsy program that could potentially benefit if these quality measures increase referrals for a higher level of care for treatment-resistant epilepsy. M. Stecker serves as an editor for *Surgical Neurology International™ Supplement, Neuroscience Nursing*. Dr. Stecker's husband receives royalties from UpToDate in the amount of \$800. Go to Neurology.org for full disclosures.

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